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Mladenov, Teodor

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INSTITUTIONAL WOES OF PARTICIPATION: BULGARIAN DISABLED PEOPLE'S ORGANISATIONS AND POLICY MAKING

Teodor Mladenov, teomladenov@gmail.com

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Abstract

This paper presents a critical study of the participation of Bulgarian disabled people's organisations in the policy-making process on national level. It describes how the 'representatives' of disabled Bulgarians become depoliticised and even depersonalised when their participation gets institutionalised through the National Council on Integration of People with Disabilities. It is argued that such an instance of 'participation' actually sustains the *status quo* of underdevelopment and dependency. A parallel is drawn with the concerns of the British disability movement. The paper ends by suggesting some tentative solutions to the highlighted problems.

Key words: disability, policy-making, participation, institutionalisation, social movements

Introduction

No reflection is independent of the social and economic conditions of its origination and development. The analysis which follows became possible within the framework of a project implemented by the Center for Independent Living – Sofia. The Center is a Bulgarian non-profit, non-governmental organisation (NGO) run and controlled by disabled people. It was established in 1995 by a group of active disabled citizens with the aim to promote equal opportunities and independent living for disabled people all over the country (CIL, n.d.). The organisation's work is explicitly based on the social model of disabilities (Oliver, 1996) and is well-known for its critical attitude towards government disability policy. Importantly, *all* the projects of this NGO so far have been funded by foreign donors. Thus, without (a) an organised group of people, sharing a common worldview and values, who accept and acknowledge certain ideas as legitimate and important – in our case this is the Center; and (b) financial resources with which to support the 'materialisation' of the ideas – in our case this is the 'outside', donor funding, the reflections which follow, albeit being sole responsibility of the author, would have never happened.

Unfortunately, because of lack or exhaustion of conditions (a) and (b), in the near future in Bulgaria a lot of other similar reflections *might not happen*. Bulgarian NGOs can no longer rely on the generous funding from foreign donors characteristic of the decade before the country joined the European Union on 1 January 2007. The gradual withdrawal of the donor's support is supposed to be compensated for by funding from

EU structural funds, but there is a clear and present danger that this change will affect negatively the 'civil character' of the sector and its independence from the state. Similar tendencies have been recognised by foreign donors themselves. In her Executive Letter, dated February 2007, Rayna Gavrilova – the executive director of the Trust for Civil Society in Central and Eastern Europe, highlights the processes of professionalisation and institutionalisation of the civil society organisations, characteristic of the last few years of the so-called 'transition period'. She notes that '[t]he increasing share of the public funding from governments and the European Union pushes organizations to improve their institutional performance. The skills of experts and professional bodies only are up to the complexity of the tasks, delegated from the public authorities to non-profit organizations' (Gavrilova, 2007). The problem which Gavrilova identifies is that this professionalisation and institutionalisation alienates NGOs from their social base – in other words, from the very people whose interests these same organisations are by default called upon to defend.

As far as the expected EU funding is concerned, it is highly unlikely that after the commencement of the new funding programmes (Ministry of Finance, n.d.) the government agencies which are supposed to redistribute the European money locally will be inclined to fund initiatives, critical towards their own departments. But the critical reading of government policies is (or at least should be) one of the main tasks of the local NGOs.

In this particular political and economic context a study of the participation of Bulgarian NGOs in the policy-making process on the national level seems quite timely. It might highlight the problems which arise when socially-oriented NGOs become dependent on state financial and institutional resources. The institutionalised participation in case is the National Council on Integration of People with Disabilities (NCIPD). It was established with the regulations of the Law for Integration of People with Disabilities (2005, art. 6) and its composition, organisation and functions were detailed in the Regulations for the Constitution and Operation of the National Council on Integration of People with Disabilities (2005). Actually, 'National Council on Integration of People with Disabilities' is the new name of an older body – the National Council on Rehabilitation and Social Integration, which had been in existence between 1996 and the end of 2004 – in other words, at stake is a case of 'participation' with more than ten years of institutional history.

Using the Law on Access to Public Information, the Center for Independent Living managed to receive the minutes from the 10 meetings of NCIPD conducted until the moment of the request – 5 during 2005 and 5 during 2006. It seems important to underline that by the time of writing this text the National Council still did not have an internet site nor was publicly present in any other way and our sole source of information on its activities were these minutes. The minutes themselves do not contain verbatim reports, but summarise the discussions. In addition, there are no publicly available studies or reports, analysing NCIPD's or its predecessor's activities. Thus, the present article ventures into an utterly non-transparent, understudied and uncharted

territory of Bulgarian disability policy making and is prone to all the conceptual risks stemming from such a deficit of information.

Traditional understanding suggests that participation of citizens in the policy-making process by means of including their representatives in institutional structures like NCIPD contributes positively to social development. But like most other self-evident ideas, this one too alerts critical thinking – especially after a decade of sterile exercises in the rhetoric of 'constructive dialogue' between the Bulgarian state and its 'partners' in NCIPD. Now, with the announced conclusion of the Bulgarian 'transition' from state socialism to liberal democracy and with the recent stepping over the European threshold, critical thought has an even greater incentive to look inside the Trojan horse called 'participation of people with disabilities' and institutionally embodied in NCIPD. No doubt, it could find there some plausible explanations for the growing gap between *talking* (about 'integration', 'equal opportunities' and 'social inclusion') and *acting*, which many people in Bulgaria regard nowadays as a social policy truism.

The following reflections are intended to outline some of the main issues haunting the process of institutionalisation of civil participation. In order to ground my critique, I will commence the analysis by showing how in the case of NCIPD this process has brought about *depoliticisation* and *depersonalisation* of the 'representatives' of Bulgarian disabled people. Further, I will position these observations within the broader context of the *paradox of institutionalisation*. This will highlight the *power aspects* of participation, which often remain neglected not only within governmental rhetoric and

theoretical discussions concerning social development, but also by the civil 'participants' themselves. Delving even deeper into this 'dark side' of participation, I will analyse the inclusion of the 'nationally representative' organisations in NCIPD as an instrument for *sustaining the status quo*. At this point a parallel will be drawn to the *participation of British disabled people's organisation* in the policy making process in order to highlight similarities, but also to grasp the specificities of the Bulgarian case. I will then outline a critique of the traditional understanding of *disabled people's needs* and its misuses with regard to *representativeness*. In conclusion, some clues for overcoming the problems with 'participation' will be presented.

Participants and their depoliticisation and depersonalisation

Let me begin with the general observation that NCIPD is too much integrated into the structures of state power for it to be able to contribute to the '*radical change* in the philosophy of social protection and a new policy approach, aimed at improving the quality of life and social inclusion of people with disabilities' (Ministry of Labour and Social Policy, n.d., p. 1, emphasis added). Note that in this case the necessity for a '*radical* change' is stated in a strategic paper of the government – the National Strategy for Equal Opportunities for People with Disabilities, and not by some 'romantically minded' NGO activists. Therefore, even the most rigid bureaucrat will find considerable difficulties in refuting the point that it is only through *radical* innovations in disability policy that the principles of 'equal opportunities', implied in the euphonic home and international policy documents, could finally be translated into practice.

The problem is that such *radical* change cannot be achieved *from inside*. The function of NCIPD is to sustain (the often idle running of) the state bureaucratic machine and not to challenge its constitution or operation. Formally speaking, this role is imposed by the law itself, which creates the National Council as a 'consultative body' attached to the Council of Ministers 'with the aim to *collaborate* in developing and implementing the policy in the field of integration of people with disabilities' (Law for Integration of People with Disabilities, 2005, art. 6; emphasis added). This means, first and foremost, lending '*support and assistance* for the implementation of the policy targeted at integration of people with disabilities' (Regulations for the Constitution and Operation of the National Council, 2005, art. 3; emphasis added). Thus, according to the rules of the institutional game the main task of NCIPD is to *collaborate, support* and *assist*, and by no means to *criticise* or *change* (let alone *radically*). The participants in the National Council have no influence whatsoever upon this ready-made institutional framework of their participation – they are expected to play a role predetermined by the bureaucrats.

Even a hurried reading of the minutes from the NCIPD meetings shows that this role is strongly *depoliticised*. The discussions which take place during these gatherings predominantly concern technical questions, which are tackled within the framework of a long ago established and taken for granted system of social relations. The system itself is in no ways challenged. Thus, for example, the main topic of two consecutive meetings of NCIPD (2nd and 3rd in 2005) was the list of goods and services commissioned by the state to the special enterprises (sheltered workshops) for disabled

people. The participants ardently discussed the entries in the list – controversial issues turned out to be the 'sesame halva', the 'wafers' (different kinds of sweets) and the 'house-painting services' (National Council on Integration of People with Disabilities, 2005a, pp. 2-3), how should the list be composed, who should be entitled to do it (National Council on Integration of People with Disabilities, 2005b, p. 3), etc. But one cannot read anywhere in the minutes anything critical about the segregational principle upon which such enterprises are based (CIL, 2003, pp. 52-53; Gill, 2005).

On a more general – let me say *ideological* – level one could find the roots of the depoliticisation of disabled citizens' representatives in the domination of the 'medical model' of disabilities (Thomas, 2002, p. 40; cf. Oliver, 1996, p. 31). This perspective reduces the problems of disabled people to their physical, mental and/or sensory 'deficits' (impairments) and detracts the attention from the disabling environmental conditions. Thus, from the medical model perspective it is '[i]mpairment *per se* [which] is of central concern – its detection, avoidance, elimination, treatment and classification' (Thomas, 2002, p. 40). Further, this conceptual framework suggests that the issues in the area of disabilities should be addressed through biomedical rehabilitation and treatment, as well as through creation of *special* places – *special* houses, schools, enterprises, institutions – where disabled people should be *specially* treated by *specialists*. In short, the medical model looks for *expert and not political solutions* to the problems encountered by disabled people (Barnes, 2003) – hence the depoliticisation of their representatives' participation in the policy-making process.

But this does not exhaust the question, for the role of the members of NCIPD is not only and not just depoliticised – it is also *depersonalised*, and at that to a degree which transforms the participants into attendants, a bunch of spectators, by default celebrating predetermined decisions (in other words, exercising 'collaboration'). The source of this passivity might again be traced back to the medical model, which reduces disabled people to passive objects of specialised interventions (Brisenden, 1986, p. 22). What is more, in the Bulgarian context the passivity is sustained by a number of institutions, beginning with the Expert Medical Commissions – the official bodies which assign disability status to individuals on the basis of medical assessment and in terms of 'percentage of lost ability to work' – and ending with NCIPD, as it paradoxically turns out to be the case, for the latter institution is explicitly designated as empowering! A disquieting symptom of the passive attitude of organisations of and for disabled people attending the National Council is the fact that *all* the decisions of NCIPD in 2005 and 2006 have been taken *unanimously*. This fact is alarmingly reminiscent of the forms of 'participation' dominating the near but already somewhat forgotten past of the state socialism in Bulgaria – the past in which the person used to be reduced to a number legitimating the arbitrary rule of the party elite.

The paradox of institutionalisation and the issue of power

It should be underlined, though, that the phenomena of depoliticisation and depersonalisation, which accompany the 'participation' of disabled citizens' representatives in the policy-making process in Bulgaria, are not confined to this

particular social group. Similar 'side effects' of institutionalisation are by no means specific to the area of disabilities. Thus, for example, in her relatively recent analysis of the development of the Bulgarian NGO sector Vera Dakova highlights that

> [t]here is a paradox for the NGOs in countries in transition – if they want to influence the state, they have to 'come closer to it' and then they are easily co-opted and distanced from their functions as civil society; if they remain firm on their civil society positions, they are easily marginalised and are not allowed access to the process of defining the development policies (Dakova, 2003, p. 44).

But this 'paradox of institutionalisation' (Stammers, 1999, p. 998) is not specific to the countries in transition either – it is typical for the life cycle of social movements in general. In contemporary society their development almost inevitably presupposes institutionalisation, but '[t]he trajectory of institutionalization is always the same, from "change" to "order," from challenging the status quo to sustaining it' (ibid.). That is why every attempt to channel citizens' discontent along the well-established institutional lines necessarily ends up with its shrinking and eventual extraction from the agenda of the groups which have initiated it. To cite Stammers (ibid., emphasis added) again, 'institutional structures are not likely to be a fertile soil through which existing relations and structures of power can be effectively challenged unless those institutions are themselves being forced to adapt and change as a consequence of further challenges from *outside* those institutions'.

The effects of the 'paradox of institutionalisation' upon disabled people's self-organisation have also been reported by other analysts in other socio-political contexts.

Thus, van Houten and Jacobs (2005) describe the professionalisation and bureaucratisation of the Dutch National Council of disabled people, which distance this umbrella structure from its social base. The authors point out that 'the Council has developed a different voice compared to that of the original movements. It is the voice of policymakers, government officials and politicians, and not the voice of its members with their daily experiences and struggles' (ibid., p. 648). Significantly, '[i]n this process, the critical consciousness and direct action of the original movement vanished in cooperating with mainstream institutions' (ibid.).

In addition, the consequences of institutionalisation might go well beyond the consciousness and operations of the co-opted groups and/or organisations. If we go back to our Bulgarian case, we will notice that the institutionally imposed and uncritical rendering of the work of NCIPD in terms of 'dialogue', 'partnership' and 'consensus' actually covers up the *power aspects* of the interaction of this structure with other collective social actors. For example, it disguises the way bureaucrats use statements made by disabled people themselves in order to silence other disabled people's statements and thus to legitimise the administratively imposed course of action. When in the middle of 2006 the Center for Independent Living – Sofia approached the High Administrative Court with a request to revoke certain normative regulations which wrongfully cut down the so-called 'social integration allowance' by binding it to the medical assessment of impairment (CIL, 2007, pp. 36-39), the defendant representing the Council of Ministers defined the request as 'ungrounded' on the basis that the challenged regulations 'were enforced with the consent of the National Council' (CIL v.

Council of Ministers, 2006). Thus, what had been said by one group of disabled people was mobilised against what had been said by another – the crucial difference between the two statements being that the former exercised 'collaboration' from the *inside*, whereas the latter strived to change the *status quo* from the *outside*.

All this leads us to yet another aspect of the 'participation' issue. Its outlines have already been drawn by hinting that a statement is never true or false on its own, but becomes one within a certain system of social relations, which presupposes a certain distribution of power. This power aspect of participation comes to the fore when one begins to reflect on the phenomena of *legitimation*. Generally speaking, to be 'legitimate' (in the broader, extra-legal sense, as indicated by Lyotard, 1984, p. 8) means to be *granted* a certain right, to be *taken for* trustworthy, representative, a reliable source of particular information, to be *permitted* to behave in a certain way, etc. It is the rituals of 'granting', 'taking for' and 'permitting' which provide for the rightfulness, truthfulness and representativeness of certain statements or actions. In this sense the NCIPD undoubtedly is '*the* legitimate… partner of the state' (National Council on Integration of People with Disabilities, 2005b, p. 6, emphasis added), for its members are *institutionally empowered to produce truths* about the problems and solutions in the area of disabilities.

It is important to underline that in the case under consideration the legitimation goes both ways. On the one hand, the involvement of NCIPD in the process of 'developing and implementing the policy in the field of integration of people with disabilities' (Law

for Integration of People with Disabilities, art. 6) contributes to the *legitimation of this policy*, i.e., to its rendering as viable, representative and reliable. On the other hand, most of the organisations of and for disabled people, which at present participate in the policy-making process on a consultative level, are *legitimate solely as conductors of the state policy* in the area. Over the years (which for some of them like the Union of the Deaf in Bulgaria amount to more than 7 decades) they have established relationships with the state, which assign to them a passive and dependent position – but at the same time these very relationships sustain them as organisations.

A suggestive parallel

At his point a suggestive parallel might be drawn with British disabled people's organisations and their relationships with the state. The outlining of the similarities and differences might be useful for understanding the Bulgarian case. Discussing the failure of 'pressure group' tactics to effect progressive change in the British disability policy making, Oliver and Zarb (1989) describe a certain type of disability-related organisations which closely resemble the 'nationally representative' organisations that we are scrutinising here. These organisations 'have, over the years, built up a relationship with the State, or the "establishment"…, which gives them credibility, but little power' (ibid., p. 224). Developing this argument further, the authors cite Borsay (1986, p. 16), who aptly points out that 'the status which flows from [these organisations'] long traditions and their connections with the "establishment" give them

a credibility and aura in government circles which more recent (and perhaps more radical) groups of disabled people cannot easily imitate'.

Oliver and Zarb (1989, p. 224) regard these structures as organisations *for* disabled people and counterpose them to 'organisations controlled and run by disabled people' or organisations *of* disabled people, which comprise the disability movement. The distinction has been influentially reiterated by Shakespeare (1993, pp. 253-254) and subsequently utilised and elaborated on by many others. For example, Drake (1996, pp. 15) underlines the lack of access to resources and power, characteristic for the Welsh organisations *of* disabled people, and points out that '[g]roups governed by disabled people tended to be weaker than other agencies. … Statutory bodies and other major providers of funding tended to work with the most professionally organised groups in the voluntary sector'.

In a similar vein, Beresford and Campbell (1994, p. 323) emphasise the differences between representative and participatory democracy, identifying the former with the British organisation *for* disabled people, while the latter – with the disability movement. They also underline the concomitant dichotomy between service provision and advocacy (ibid., p. 320). Similarly, Drake (1996, p. 19) found in his study of Welsh voluntary organisations that disabled people were more concerned with 'campaigning for social change', than with 'the provision of specialised and segregated services'. He attributed this difference to the allegiance of the former to the social model of disabilities (ibid.) and, by implication, of the latter to the medical model. Consistent

with this rendering of the issue, an earlier paper by the same author (Drake, 1992, p. 276) utilises the distinction between dominant group(s) and subordinate groups, identifying the service providers with the former and disabled people – or 'consumers' – with the latter.

In addition, in the already cited piece Shakespeare (1993, p. 250) points to direct action as a central characteristic of disabled people's self-organising. He also underlines the extent to which political transformation in the area of disabilities in US and Britain (his two case examples) was not achieved from 'inside' the system, utilising existing systemic resources, rules and regulations, but from 'outside' it: 'Political change did not rely on the lobbying of professionals, or the use of electoral methods. … The solution has been grass roots campaigning activity, self-organisation, direct democracy, and direct action' (ibid., p. 253).

Table 1 summarises these diverse, but mutually coherent and reinforcing views of the British disability scholars, enlisting a set of dichotomies.

Table 1. Summary of the dichotomies

Organisations *for* disabled people	**Organisations *of* disabled people**
traditional charities, pressure groups	disability movement, consumer groups
able-bodied professionals are in power	disabled people are in power
have access to government funding	are under-resourced, under-funded
enjoy government support	lack government support

representational democracy	participatory/direct democracy
service provision, charity	campaigning and advocacy
medical model	social model
dominant	subordinate
conformist or reformist	radical
committed to political negotiations, utilising existing power structures	committed to direct action, utilising tactics outside traditional power structures
co-opted, inside the system	independent, outside the system

British analysts and activists have good historical and socio-political reasons to sustain these dichotomies. The disability movement in Britain has won a number of important battles along the lines separating the two terms in the table. Among them are the British disability rights (anti-discrimination) legislation, the ascendance of the Direct Payments schemes, and more recently – putting the Independent Living approach explicitly on the government policy agenda (Prime Minister's Strategy Unit, 2005). Not least, the very existence of a radically critical journal like *Disability & Society*, from where most of the conceptual food energising the present text is derived, must also be counted towards this impressive list of achievements.

While many of the binaries in the Table 1 neatly fit the Bulgarian context too, the transposition of its organising principle – the distinction between the organisations *for* and organisations *of* disabled people – turns out to be problematic. The point is that most of the Bulgarian organisations *of* disabled people, that is, 'controlled and run by

disabled people', display some or all of the characteristics, attributed by British analysts and activists exclusively to the 'organisations *for*'. At the same time – and as the present analysis suggests – these organisations function as primary supporters of the *status quo*. Thus, the 'nationally representative' groups in Bulgaria which are statutory defined as 'organisations *of*' on the basis of their membership (see the next section for details), receive significant government funding (CIL, 2004, pp. 51-52; 2003, pp. 65-68; 2002, pp. 67-69), while their activities are confined almost exclusively to the area of charity and service provision (CIL, 2004, p. 55; cf. Union of Invalids in Bulgaria, n.d.) and are deeply rooted in the medical model of disabilities (Mladenov, 2007).

In addition, strictly speaking, there has never been a 'disability movement' in Bulgaria – at least not in the sense of a 'mass action', indicated by Shakespeare (1993, p. 254). The widely recognised as the most critical organisation on the Bulgarian disability arena – the Center for Independent Living – has never strived to increase its membership. Actually, albeit run and controlled by disabled people, the Center does *not* identify itself as a membership-based organisation. The guiding principle of its actions has always been to advocate for certain values and to promote certain principles – to wit, the values of the independent living and the social model of disabilities (CIL, n.d.). In brief, the organisation has strived to represent ideas, not people.

Consequently, the main distinction which organises the resistance along the aforementioned lines (i.e., service provision and charity vs. rights and advocacy, medical vs. social model, reforms vs. radical innovations, etc.) in the Bulgarian context

might better be rendered *not* terms of 'organisations *for* vs. organisations *of*', but in terms of state-subsidised and supported organisations vs. organisations which do not (and cannot) count on state funding and support and which remain outside the official power circles. Such a distinction has been utilised in CIL's (2002 p. 50) own analyses:

> The disabled organisations [in Bulgaria] can be divided into two main groups, nation-wide organisations *subsidised by the state budget*, and indigenous associations of people with disabilities, which are *not supported by the government*.
> (…)
> It has still not being widely accepted that *all disabled organisations* have a role to play in the development of disabled policy. (emphasis added)

Disabled Peoples' International (1986, p. 21, cited in Oliver & Zarb, 1989, pp. 232, emphasis added) stated that 'our own organisations should assert that they were the *true and valid voice of disabled people and our needs*'. Yet, the Bulgarian experience suggests that in certain (socio-politically specific) contexts it might be precisely this unified, 'valid voice of disabled people' that might become the primary obstacle before changes and the main supporter of the *status quo*. And the concept of 'our needs' – the needs of disabled people – might turn out to be among its main tactics. A final glimpse at NCIPD is about to illustrate this point.

The question of needs and representativeness

The concept of *needs* can be used not only as an instrument for empowerment (as in the last quote form DPI), but also as a means for sustaining institutionally-convenient forms

of ‘participation’. In a welfare-oriented context, this concept suggests that every individual *possesses* certain needs, which can be *objectively* identified, assessed and described as they are *in themselves*. The underlying assumption is that once social policies are harmonised with these needs narratives, they will start to reflect the *real* situation of their addressees and this will enhance their effectiveness (cf. Oliver, 1996, pp. 64-65). Such an understanding is implied in the Regulations for the Constitution and Operation of the National Council (2005, art. 3), which pose as second in the list of the major functions of this body to ‘research and analyse the needs of people with disabilities, related to integration’. Thus, the Regulations suggest that it is the *knowledge of needs* which should ground the ‘support and assistance’ that NCIPD is expected to provide for the implementation of the state policy in the area of integration of disabled people.

The problem with the traditional concept of needs is that it presupposes the *independence* of the interests and wants from the activities for their identification, assessment and description. In other words, according to the dominant view the needs exist objectively, they are ‘out there’, in ‘reality’, where they passively ‘wait’ to be discovered and taken into account – *the way they are in themselves*. But the critics of the traditional social development approaches question this notion. They highlight the process through which the people from the target group ‘shape their needs and priorities to match the project’s schemes and administrative realities, validating imposed schemes with local knowledge and requesting only what is most easily delivered’ (Mosse, 2001, p. 24). In this process ‘the project’s institutional interests become built into community

perspectives and project decisions become perfectly "participatory"' (*ibid.*). Similar observations have been made in the area of disabilities (cf. Beresford and Campbell, 1994, p. 319).

The crucial thing is that the understanding of 'what people need' depends on *who* asks and *what* do the respondents expect to gain from the inquirer(s). It is interesting to note that such a critical view lurks even in a governmental piece of writing like the National Strategy for Equal Opportunities for People with Disabilities. The Strategy (Ministry of Labour and Social Policy, n.d., pp. 3-4) explicitly states that it is because most of the disabled people in Bulgaria perceive themselves as 'passive recipients of social aid' that 'many of them continue to expect state benefits in cash or in kind'.

If we now turn back to NCIPD, we will notice that the main bearers of the knowledge about the 'needs' of disabled people there by default are the 'nationally representative' organisations of and for disabled people. Such an understanding is implied in the legal requirement for 'representativeness' of these organisations, which is detailed in the already cited Regulations for the Constitution and Operation of the National Council (2005, art. 8) in terms of *territorial coverage and membership*: the territorial structures of the organisations should 'cover more than 30 percent of the municipalities in the country'; the organisations of disabled people should 'have no less than 1600 members, no less than 50 percent of whom should be people with permanent disabilities'; the organisations of blind-deaf people should 'have no less than 400 members', etc. In other words, the greater the number of members with disabilities (identified as such by their

medically certified impairment) and the territory 'covered' by the organisation, the more representative it is, that is, the more *truthful* the re-presentation of the interests and needs of disabled people will be. And this probably would be correct if the needs of disabled people were really 'out there', objective and independent of the circumstances of their identification, articulation and description, waiting to be 'assessed' and taken into account in the policy-making process.

But the articulation of needs and interests is a much more complex issue, for it is always a product of the interaction between the 'inquirer' and the 'inquired' (who, in our case, coincide with the 'representing' and the 'represented') – an interaction in which the 'inquirer' is by default in the position of power, while the 'inquired' usually aims to gain maximum benefit with minimum efforts out of this power (Mosse, 2001, p. 24). Hence, as long as the 'nationally representative' organisations continue to focus their efforts on provision of free medical supplies for their members, on organising excursions and arranging talks with medical doctors, nurses and social services employees (Mladenov, 2007; cf. Union of Invalids in Bulgaria, n.d), their constituency will hardly demand anything other than cheaper medical treatment and up to date information about how to overcome the myriad of bureaucratic obstacles on their way to getting their monthly allowance of 30 Leva (15 Euro) for 'social integration'. In other words, the 'culture of dependency' (Barton, 1993, p. 239) will continue to reproduce itself and disabled people will continue to dwell in their 'learned helplessness' (ibid.). And the 'radical change' prescribed by the National Strategy (Ministry of Labour and Social Policy, n.d., pp. 3-4), will time and again fail to happen, and the bureaucrats will

time and again wonder why Bulgarian disabled people continue to perceive themselves as ‘passive recipients of social aid’ and ‘to expect state benefits in cash or in kind’.

Conclusion

Let me restate the main stake of the present text – to underline that incorporation of civil participation into established institutional structures bears a significant risk of increasing state power at the expense of disempowering civil organisations. The analysis of NCIPD’s regulations, functioning and membership criteria showed that this ‘swelling’ of power is inextricably bound up with depoliticisation and depersonalisation of citizenry. On its behalf, the depoliticised and depersonalised citizenry could easily be turned into a handy instrument for legitimising the *status quo*.

A possible way out of this impasse of the interaction between people and state is to distinguish *different levels or degrees of participation*, namely:

(1) participation as *accepting and supporting* predetermined decisions, which inevitably leads to their one-way legitimation;

(2) participation as *choosing* between predetermined alternatives, which, although providing more opportunities for reaction, still leads to one-way legitimation of ready-made decisions;

(3) participation as *developing* alternatives within the framework of a predetermined system of relationships, where the processes of sustaining the *status quo* begin to loosen its grip;

(4) and finally, participation as *changing* a particular system of relationships and therefore – particular patterns of power distribution. It is on this fourth level that the *status quo* might successfully be overcome.

These distinctions echo the 'ladder of citizen participation' that Sherry Arnstein (1969) introduced almost half a century ago. They enable us to realise that the participation of the representatives of disabled Bulgarians in NCIPD is limited to the levels (1) and (2), which roughly correspond to the three rungs of 'tokenism' in Arnstein's concept metaphor (ibid., p. 2). Yet, in most of the cases this token character of participation remains unnoticed, because the uses of the notion of 'participation' in the dominant rhetoric are meant to designate levels (3) and (4), whereas what happens in practice is confined to first two levels. The reason for this is that

> participatory goals including ideas about 'people's knowledge' and 'participatory planning' are significantly (if not primarily) oriented upwards (or outwards) to legitimize action, to explain, justify, validate higher policy goals, or mobilize political support rather than downwards to orientate action (Mosse, 2001, p. 27).

Hence the gap between 'talking' and 'acting', which – as noted at the beginning of the paper – is particularly relevant for the Bulgarian disability policy.

This policy will undergo the much needed 'radical change' only if disabled people's organisations succeed in climbing up the 'ladder of participation'. But this would be impossible in institutional terms as long as NCIPD retains its present depoliticised and depersonalised form. Therefore, a radical change in the National Council itself is called for. First and foremost, the criteria for inclusion in this body should be altered – they

should be based not on the number of members and territorial coverage, but on the value commitments of the organisations and their track record in fighting for equalisation of opportunities for disabled people (CIL, 2007). Organisations controlled and run by disabled people should have a majority in the structure thus reformed, although – as already discussed at lengths – this would not by itself guarantee their commitments or allegiance to the 'best interests' of their constituency. It is certainly true that non-disabled people should not speak *on behalf of* disabled people (Drake, 1997, p. 643). The point is that there are also significant dangers in disabled people being empowered to speaking *on behalf of* other disabled people. The effects from this on the *status quo* can be really cementing.

Hence the second suggestion. Disabled people's organisations who manage to climb up the 'ladder of participation' by engaging in *real* policy making through *reformed* structures like NCIPD should have as their (urgent) priority the securing of funding and support for what I would like to call here *decentralised, independent, local resistances*. Thus, the participants in the national policy making should not endeavour to speak *on behalf of* other disabled people, but should strive to enable local groups and organisations of disabled people to speak and act *for themselves*. That way they would effectively multiply local resistances to ubiquitous disablist pressures, permeating contemporary Bulgarian society. This suggestion sides with Beresford and Campbell's (1994, p. 324) observation that '[i]t makes sense to spend more of our energy participating in our own initiatives rather than being represented in service systems'. It is also akin to van Houten and Jacobs' (2005, p. 653) call towards restructuring the

main Dutch umbrella organisation into a support structure 'that acts as a link to funding and policy institutions', with the aim to create 'space for new social practices and movements to develop'. Finally, it is consistent (although not identical) with Oliver and Zarb's (1989, p. 235) suggestion that

> the disability movement must develop a relationship with the State so that it can secure proper resources and play a role in changing social policy and professional practice. On the other hand, it must remain independent of the State to ensure that the changes that take place do not ultimately reflect the establishment view and reproduce paternalistic and dependency-creating services, but are based upon changing and dynamic conceptions of disability as articulated by disabled people themselves.

In effect, without going into the blind alleys of identity politics, the proposed changes might provide for the much needed disability movement – or rather, disability movements – to finally emerge and gain momentum on the Bulgarian cultural, social and policy arenas.

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